

# Should Patients Have a Greater Role in Valuing Health States?

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## Abstract

Currently, health state values are usually obtained from members of the general public trying to imagine what the state would be like rather than by patients who are actually in the various states of health. Valuations of a health state by patients tend to vary from those of the general population, and this seems to be due to a range of factors including errors in the descriptive system, adaptation to the state and changes in internal standards. The question of whose values are used in cost-effectiveness analysis is ultimately a normative one, but the decision should be informed by evidence on the reasons for the differences. There is a case for obtaining better *informed* general population preferences by providing more information on what it is like for patients (including the process of adaptation).

## 1. Background

International agencies such as the National Institute for Health and Clinical Excellence (NICE) are becoming increasingly prescriptive about different aspects of the methods of economic evaluation.<sup>[1]</sup> A key aspect of economic evaluation is the assessment of the benefit of healthcare interventions, which includes the use of QALYs. The QALY combines HR-QOL with the value of length of life. This is calculated by assigning a value to HR-QOL using a scale on which full health equals 1 and health states regarded as bad as being dead equalling 0. The current NICE guidance has extended to prescribing the source of the value for HR-QOL. The Washington Panel on Cost-effectiveness in Health and Medicine has been very influential in its advocacy of the use of the general population for valuing health states.<sup>[2]</sup> This has been reflected in economic guidelines produced in England and Wales and in Canada.<sup>[1,3]</sup>

A widely used approach is to use health state values generated by a generic preference-based measure, such as the EQ-5D, Health Utility Index-3 (HUI-3) and the SF-6D, and valued by a sample of the general population.<sup>[4-6]</sup> Using this approach, respondents are asked to imagine health states defined in terms of generic dimensions of health, such as mobility, self care, usual activities, pain/

discomfort and anxiety and depression dimensions from the EQ-5D.

The values can be elicited using a number of techniques, including visual analogue scales (VAS), time trade-off (TTO) and standard gamble (SG).<sup>[7]</sup> The rating scale asks respondents to rate a health state on a line, where the upper anchor is full health and the lower anchor is death or the worst imaginable state. Most economists advocate one of the other techniques since they are 'choice-based': SG asks respondents to consider the risk they would be prepared to take in order to return to full health (e.g. risk their life) and TTO asks respondents how many years of life they would be willing to give up to move to full health. An interviewer, often using visual props to assist the respondent with the valuation task, usually administers these tasks.

The conventional approach to valuing health states essentially asks respondents for their 'off the cuff' *ex ante* valuation of the states. The resultant values have sometimes been described as social values but this is a misleading term since respondents are being asked to value the states from the perspective of being in the states. The resultant set of health state values is really an average of the individual valuations of those states.

As economics becomes more influential in health policy, it seems appropriate to revisit the arguments for using the general population to obtain health state values compared with alternative

possible sources, such as those who are actually in the state (i.e. the patient). In this paper we define the patient as the person experiencing the health state, whether or not they are seeing a health professional about their health. The aim of this paper is to review the debate regarding whether patient or general population values should be used in health state valuation for use in economic evaluation. We consider the reasons for the differences between patients and then examine the normative arguments for and against using values from these sources.

We begin by examining the importance of the discrepancy between general population and patient health state values in economic evaluation in healthcare. Section 3 examines some of the reasons given for the discrepancy between these sources of value, since this has important implications for the normative question of whose values should be used. Section 4 examines the various normative arguments for and against using these two sources of values in economic evaluation. Finally, section 5 explores the implications for policy and research in this field.

## 2. The Importance of Whose Values are Used

There is evidence of significant discrepancies in health state values by illness experience and, in general, the evidence points to patients giving health states a higher value than do members of the general population.<sup>[8-12]</sup> The extent of this discrepancy is much stronger where patients value their *own* health state and it is in this context that we consider the question of whose values should be measured. The potential importance of this difference can be seen in the example of colostomies where patients with colostomies rated the HR-QOL of living with them as 0.92 compared with a rating of 0.80 from those without colostomies.<sup>[10]</sup> The incremental gain from avoiding colostomies and restoring patients to full health would be more than twice as large using estimates from the non-colostomy sample than those of the patient sample.

Comparing patient and general population samples is difficult because of variation in non-health-related background characteristics, such as sociodemographic variables. Analysis of the UK EQ-5D valuation data set found some systematic variation of TTO by age, sex and marital status and the US valuation of EQ-5D has found significant ethnic effects.<sup>[13,14]</sup> However, the size of the differences from these characteristics in general population samples tends to be quite modest compared with the differences arising from the health state descriptive system itself.<sup>[15]</sup>

Furthermore, a recent paper by Insinga and Fryback<sup>[16]</sup> examined the differences in a way that controls for background characteristics. They compared respondents' own VAS health state values for a set of EQ-5D health states with those estimated from a social VAS tariff using the UK Measurement and Valuation

of Health (MVH) data set.<sup>[17]</sup> While many health economists would not regard VAS as a cardinal measure of utility, it nonetheless has a clear monotonic relationship to choice which is based on methods such as SG and TTO.<sup>[7]</sup> The differences found in this study were significant and they varied by the severity of the state. For the five incremental differences that Insinga and Fryback<sup>[16]</sup> examined, the discrepancies in health state valuations led to incremental differences that were 73–275% larger using population ratings than self ratings. It is not hard to see that this level of discrepancy would have substantial implications for the incremental cost-effectiveness ratios (ICERs). In the context of NICE, where many interventions have ICERs of between 20 000 and 30 000 per QALY, discrepancies of 2-fold or more would have major implications for funding decisions.

## 3. Why Do These Discrepancies Exist?

Previous discussions of this subject have tended to ignore the reasons for differences between general population and patient health state values and move straight into a normative debate. However, Ubel et al.<sup>[18]</sup> have argued that the causes of the discrepancies may in themselves have implications for whose values should be used. This section is broadly based on their proposed distinction between three causes of discrepancy: (i) patients and the general population do not value the same state; (ii) they use different measuring rods; and (iii) patients experience shifts in values that are not anticipated by the general population.

### 3.1 Valuing Different States

Eliciting values from the general population requires some means of describing the health state to the general population sample. An important potential source of discrepancy in the values provided by the general population and patients is that the description provided to the general population may not accurately describe the state. The descriptive system may be insensitive to subtle differences within a dimension or simply miss out important dimensions of health altogether. This has been well illustrated by the Insinga and Fryback<sup>[16]</sup> study of VAS data from the UK MVH survey, where the difference between general population VAS ratings of hypothetical states and their rating of their own health state by VAS was probably due to the limitations of the EQ-5D descriptive system. Most of the difference was accounted for by the discrepancy between the respondent's self-rating and their separate rating of the EQ-5D state that coincidentally described their own health. While improving the descriptive systems can reduce this problem, it can never be entirely overcome.

Ubel et al.<sup>[18]</sup> also suggest that general population respondents may focus on the negative aspects of a health state and ignore the

remaining positive features, especially when the trade-off is with death. This focus may be the result of a simplification or focus that is centred on those things directly affected by the event rather than affecting the person's broader life. Again, there is a mismatch between what the general population value and the patient's experience. Bringing these broader aspects of life to the attention of the respondent could reduce this mismatch.

### 3.2 Different Scales of Measurement

A widely accepted phenomenon in the QOL research literature is the notion of 'response shift'.<sup>[19]</sup> One aspect of this phenomenon is a change in the way respondents report their QOL along different dimensions, despite there being no underlying change. Response shift refers to a change in internal subjective standards that may be due to aging, changing comparator groups or other changes in circumstances. It could be seen as a form of adaptation to the condition. For example, what an elderly person with chronic health problems means by different health state values is likely to differ from a healthy young person. The problem of response shift is greatest with evaluative questions in which respondents are being asked to provide an overall value for their HR-QOL, such as a VAS or TTO. This makes comparisons between responses obtained from different patient groups problematic as we cannot be sure that they are using the same measuring rod.

Related to the notion of differing scales of measurement is the distinction between patient and general population perspectives. A general population sample is being asked to take an *ex ante* perspective and imagine or predict the likely impact of a theoretical future state on their utility, whereas patients are being asked to adopt an experiential perspective in which they are asked to value their current state of health. There may be important normative reasons for favouring one perspective over the other.

People are not very good at predicting future preferences. Kahneman and Snell<sup>[20]</sup> found that individuals' predictions of how their preferences would change over time were not accurate. For example, respondents were unable to predict their preferences for different ice cream flavours over a period even as short as 1 week. If this is difficult to predict, how much more so will be preferences over health profiles that individuals are often unfamiliar with because of not having had prior experience of them?<sup>[21]</sup>

### 3.3 Adaptation to the State

People are likely to adapt to their state of health in a number of ways, both physically and emotionally. Physical changes include the acquisition of new skills to help cope with any disability, such as learning to use a walking cane. A person may also change the things they do in order to limit the impact of their disability or

illness. For example, following a major knee injury, someone who once played football may take up a sport that has a lower impact on his or her knees.

The response shift literature also refers to psychological adaptations. These include a shift in the weighting that people place on different aspects of HR-QOL and, more fundamentally, changes in their view of what matters in life. For example, someone may feel that work has become less important in his or her life. Other people may forget about past capabilities and the pleasures they brought. Others may reflect more on life and experience radical changes in values and what matters to them. People may also lower their expectations of what they can achieve. While some of these changes may be regarded as laudable, Menzel et al.<sup>[22]</sup> argue that some of the psychological changes may be seen as less desirable, such as cognitive denial and suppressed recognition of full health. There is also some doubt about the appropriateness of patients lowering their expectations.

General population respondents currently in good health may fail to take into account such adaptations to the health state. When they first read the description of a state, their valuation may reflect an initial response to, say, going blind, rather than reflecting on what it would really be like for an extended period. When asked about adaptation, it has been found that people tend to under-predict their ability to adapt.<sup>[23]</sup> This would tend to result in lower general population values compared with patient self-reported values because of the general population's focus on their initial response to the health problem rather than their ability to adapt, whereas the values of patients will depend in part on how long they have experienced the state. Those who have only just started to experience the health problem may have values similar to the general population; however, this theory predicts that, as patients, they will adapt over time and thus their valuations should increase.

Ubel et al.<sup>[18]</sup> also suggest two other closely related concepts. The first is the contrast effect where the importance of a particular bad or good event is moderated by contrast effects, i.e. someone experiencing a bad illness may be less affected by a minor illness than someone who has not experienced major illness before. More generally, Ubel et al.<sup>[18]</sup> talk about shifting inter- and intra-personal comparisons, i.e. our evaluation of our current health state may be partly determined by what health state our peers are in and by our own past experiences. This relates back to the earlier discussion of changing internal standards. Both patients and members of the general population will be affected by this, but valuations of the same state will be different depending on the extent that patients with chronic health problems mix with people with health problems greater than their own.

The impact of adaptation, contrast effects and shifting comparisons on the size of the discrepancy between patient and general

population valuations will depend on the descriptive system being used. A degree of physical adaptation to physical disability is already incorporated into those descriptive systems that have dimensions such as role and social functioning (e.g. SF-6D) or usual activities (e.g. the EQ-5D).<sup>[6,17]</sup> The developers of the HUI-3 excluded these social dimensions of health, in part to remove adaptation. However, all of the generic descriptive systems take some account of psychological adaptation through dimensions concerned with mood (such as anxiety, positive affect and depression).<sup>[4-6]</sup> Indeed, it could be argued that the wording of many of the other dimensions, such as those concerned with physical functioning and pain, contain a significant element of self-evaluation and so also incorporate a degree of adaptation. For example, does a 90-year-old person reporting 'some problems with mobility' on the EQ-5D really mean the same thing as a 25-year-old reporting this level? Whether it is appropriate from a normative point of view to take any account of adaptation is explored in the next section. However, it would seem that existing preference-based measures take some account of adaptation.

## 4. Normative Arguments

### 4.1 For Patient Values

Welfare economics postulate that an efficient allocation of resources is achieved where, among other things, the consumer is sovereign and provided that a number of stringent assumptions are met. An important normative position (or value judgement) in welfare economics is that the well-being of a society is simply the aggregation of the utility of individual members of society. In other words, it asserts the supremacy of an individual's valuation of their own well-being. This implies that it is the preferences of the losers and gainers from a public programme that should be elicited, and not a sample of the general population who will be unaffected by the change; this would seem to suggest that patient values should be used.

One response to this is that current patients do not represent all those likely to be affected by the set of decisions being made. It could be argued that every citizen in a public system has an option to use the service and so may be gainers and losers, meaning that the general population would be a good proxy. However, this presumes that all citizens have an equal chance of receiving all forms of care, which is unlikely. Therefore, welfare economics does not seem to offer a clear argument for either approach.

The argument for using patient values seems to hinge crucially on the fact that patients know the health states better than someone trying to imagine them. The main advantage of this approach has

been argued by Buckingham:<sup>[24]</sup> "To ask a person of 20 how she/he will value health at the age of 70 is to ask an enormous amount of their imagination. To ask a 70 year old how important their health is to them is likely to result in far more valuable information." Given the evidence that general population values are poor proxies for those of patients, this implies that patient values should be used. However, it should not be forgotten that the use of patient values to inform social decisions is a normative judgement. This would imply that society wants to incorporate all the changes and adaptations that occur in patients who experience states of ill health, an implication that is addressed in section 4.2.

### 4.2 For *Ex Ante* General Population Values

Outside of conventional welfare economics, health economists have generally been more concerned with meeting the information needs of the decision maker.<sup>[25-27]</sup> In public health systems, this has been taken to mean the adoption of a societal objective, such as the maximisation of health (subject to equity concerns), rather than the conventional individualistic perspective of utility maximisation. The Washington Panel on Cost-effectiveness in Health and Medicine, for example, advocated a social perspective for cost-effectiveness analysis and argued that: "A logical extension of that reasoning would suggest that the best articulation of society's preferences for a particular state would be gathered from a representative sample of fully informed members of the community."<sup>[2]</sup> The Washington Panel went on to use the 'veil of ignorance' to support the use of community values, where "a rational public decides what is the best course of action when blind to its own self-interest, aggregating the utilities of persons who have no vested interest in particular health states seems most appropriate."<sup>[2]</sup>

The social perspective for publicly funded services can also be supported on the grounds that it is tax funded.<sup>[3]</sup> A related argument is the insurance perspective, where resource allocation decisions in healthcare are akin to the decisions about which services should be covered by an insurance package.<sup>[28]</sup> Public funding can essentially be seen as public insurance and so it is the *ex ante* public preferences that should be used to value health states.

However, a social perspective does not imply the use of general population values any more than welfare economics implies patient values. While members of the general public want to be involved in healthcare decision making, it is not clear that they want to value health states.<sup>[29]</sup> Even behind the 'thin' veil of ignorance suggested by the Washington Panel, respondents might prefer that the values of those experiencing the health states, i.e. patient values, be used.

### 4.3 Informed General Population Values

The normative arguments reviewed in sections 4.1 and 4.2 do not consider the causes of the discrepancy between patient and general population values. Ubel et al.<sup>[18]</sup> and Menzel et al.<sup>[22]</sup> have argued that this offers a more informative route for considering whose values to use in resource allocation.

The main normative debate seems to be around the extent to which adaptation should be taken into account in the health state values used to inform resource allocation. Members of the general population are likely to know little about adaptation to illness and therefore this will not be reflected in their health state values. The choice between patient and general population values really comes down to the extent to which these changes should be taken into account. Menzel et al.<sup>[22]</sup> tried to distinguish between 'laudable' adaptations, such as skill enhancement, activity adjustment and even altered perception of health, and less desirable changes such as cognitive denial of functional health, suppressed recognition of full health and lowered expectations. There may also be some concern regarding differences arising from the contrast effects or shifting comparisons identified by Ubel et al.<sup>[18]</sup>

It has been argued that it is difficult to justify the extreme viewpoints of using only patients or uninformed members of the general population to obtain preferences for health measures.<sup>[30]</sup> Patient values incorporate aspects of adaptation, such as the lowering of expectations, that may be regarded as unacceptable for public resource allocation decisions. Furthermore, patient values are context based, reflecting their recent experiences of ill health and the health of their immediate peers. It can also be argued that patient values cannot be compared between conditions. On the other hand, the current paradigm of eliciting preferences from the general population yields values that are largely uninformed by what it is actually like to be in the state.

There is a third position that accepts the general normative position that, ultimately, it is the values of the general population that are required to inform resource allocation in a public system but that respondents should be provided with more information on what the states are like for patients experiencing them. This position has recently been put forward by a number of commentators on the subject and would imply the use of informed general population values.<sup>[18,22,30]</sup> However, this would require the development of explicit methods for providing better ways of conveying information about the states to the general population respondents. The ways that this can be achieved are examined in the next section, but could include improvements in the health state descriptions and the provision of more information on the size and nature of the adaptation experienced by patients over time. This position would be consistent with the original recommendation of

the Washington Panel that *informed* general population values should be used.

## 5. Implications for Policy

### 5.1 The Impact of Using Direct Patient Values

It has been argued that the use of general population values benefits patients.<sup>[2]</sup> This is based on the observation that the general population tend to give a lower health state value than do patients. Therefore, for any intervention aimed at curing or preventing a condition associated with ill health states, general population values will generate a larger gain. This argument is an extremely pragmatic one rather than a point of principle; nonetheless, it is worth addressing this given the concern that moving to patient values may prejudice them in some way.<sup>[2]</sup>

The argument is more complex than suggested by the Washington Panel. General population values will give a lower value to saving the lives of the unhealthy than the healthy, which would not be in the interests of most patient groups. Giving lower values to the lives of ill people means that life-saving interventions will look less attractive than if patient values had been used, and this is on top of the lower life expectancy usually associated with medical conditions (commonly referred to as the double jeopardy argument). It has also been shown by Lenert et al.<sup>[31]</sup> that the general population may undervalue movements between severe states. This argument is based on an application of prospect theory that suggests an 's'-shaped utility curve over gains and losses.<sup>[32]</sup> Given the fact that the general population will have a higher reference point, movements between severe states will register little change since it takes place at a shallow point on the curve. Patients have a lower reference point and, hence, any movement will be at a steeper point further up the 's'-shaped curve. This difference may also operate at a more intuitive level; for example, at extreme levels of disability the general population may be insensitive to small improvements in mobility that are highly valued by patients.

In the context of cash-limited systems, it is not so much a question of benefiting patients *per se*; rather, it is about the direction of resource allocation. The increased use of patient values will not prejudice patients as a whole but will result in a redirection of priorities. This may include a movement away from curative measures aimed at achieving perfect functioning towards more life-saving interventions, and perhaps at interventions that achieve small improvements to those in most serious functioning problems. It may also result in a change in the weight given to different aspects of QOL, such as mental health and pain.

## 5.2 Strategic Behaviour

A common concern in the contingent valuation literature is that respondents will aim to maximise their interests, for example by overstating the impact of a condition on their HR-QOL in order to get treatment (though whether they would exaggerate the improvement after treatment is less clear). Again, this is a pragmatic issue and not a point of principle. Furthermore, it is a problem that may already exist with use of self-reported HR-QOL measures such as the EQ-5D in which patients can exaggerate the impact on their state of health. There is little concrete evidence on strategic behaviour in healthcare; however, using these instruments on patients unlikely to be affected by the decision being made could reduce the risk.

## 6. Implications for Research

This review has highlighted a number of important avenues for future research. One is to develop methods for eliciting the values of those experiencing the state of health. The second is to develop ways to generate more informed general population values in order to examine the views of the general public on the role of patient values. While such research may not resolve the fundamental normative judgements that need to be made, they do provide important factual evidence.

### 6.1 Measuring Patient Values Using Moment Utility

Moment utility (MU) avoids the problems associated with recall. There is substantial evidence that people are generally poor at recalling their experiences. People recalling past experiences tend to be subject to a range of biases, such as ‘peak-end’ effects where they tend to focus on their peak experience and their last experience and, consequently, weight these experiences more heavily than the rest.<sup>[21,33,34]</sup> It has been observed, for example, that people who experienced two identical pain profiles in which one has an extra period of lower-level pain at the end say in retrospect that they prefer the profile with more pain.<sup>[23]</sup>

The notion of MU was proposed by Kahneman<sup>[23]</sup> to overcome the biases inherent in either trying to recall experience or to predict it. It was originally proposed as a measure of happiness, though it can be applied to health, where the total happiness of an individual over a period of time is simply the sum of every moment experienced.<sup>[32]</sup> The ideal method for measuring MU would be to ask someone to give his or her level of utility at every moment in that period.

Asking patients to value their own health, and to do so sufficiently frequently for analysis, raises some major practical problems. By definition, many patients are quite unwell and may be unable or unwilling to undertake complex and intrusive valua-

tion tasks. There may also be ethical concerns with asking terminally ill patients to imagine scenarios involving either the risk of death or shorter life expectancies. These are very real practical problems, particularly in the use of TTO and SG, but they should not be exaggerated.<sup>[35]</sup>

The psychological work on experienced utility mainly uses rating scales that are criticised by health economists for lacking the choice context required to obtain a preference value, such as achieved in SG, TTO or WTP.<sup>[36]</sup> However, the use of choice-based methods presents a paradox: the accepted choice-based techniques for valuing health states, such as SG or TTO, require a patient to value their existing state by imagining what it would be like to be in full health, which they may not have experienced for many years. For patients who have lived in a chronic health state such as chronic obstructive airways disease or osteoarthritis, for example, the task of imagining full health may be as difficult as a healthy member of the general population trying to imagine a poor health state.

### 6.2 Valuing Health States Linked to a Generic Descriptive System

There is a link between the generic preference-based measures that are currently valued using general population values and patient values, and that is to revalue them using patient values. This has been undertaken with some success in the valuation of the SF-12, where the SF-12 was administered alongside a self-completed TTO question in a general population sample that included patients with a range of medical conditions.<sup>[37]</sup> Weights were estimated using the SF-12 by regressing its items onto the TTO response. This approach has also been used on a patient sample to revalue the EQ-5D and SF-6D.<sup>[38,39]</sup> This pragmatic approach is limited by the sample of patients used, because there is inevitably a bias in those who complete HR-QOL instruments. Furthermore, application of these generic instruments presumes that their descriptive systems adequately capture the impact of a patient’s experience. However, it does offer one avenue for starting to examine the implications of using patient values more directly.

### 6.3 Eliciting Informed General Population Values

In a recent editorial comment in *Quality of Life Research*, Fryback<sup>[30]</sup> concluded: “For the quality of life research community the challenge is how to move beyond asking the public to value telegraphic health profile descriptions. We need to define an elicitation paradigm to make realistic use of patient’s perceptions and values in societal evaluations.” This is going to be a radical departure from current thinking, which seems to promote a view that people’s preferences are simply there to be elicited and that

general population values are in some way pure and should not be contaminated. In practice, general population health state valuations are being constructed at the time of questioning and so they reflect their immediate reaction to a state rather than any consideration of the likely longer-term considerations. We have argued earlier in this review that most descriptive systems incorporate some degree of patient evaluation through the mood dimension and those dimensions concerned with social health. Seeking more informed general population preferences is really a question of how much more information to give them.

Current descriptive systems, such as the EQ-5D, have been criticised for being rather abstract and not describing what the health state is like for the patients. Remarkably little effort has gone into making health state descriptions more realistic; however, there has been work on, for example, simulating health states using spectacles to reproduce visual impairment (Aballéa and Tsuchiya<sup>[40]</sup>) or using computer simulators. There may be scope for showing videos of patients being interviewed about their condition; however, inevitably, this would involve a trade-off between over burdening the general population and achieving sufficient realism.<sup>[41]</sup> It also seems appropriate to allow respondents more time to reflect on different health states, and perhaps to deliberate with friends and relatives as well as other respondents. Such a process may better reflect the way some people make such decisions in reality. This process of health state preference elicitation takes account of the fact that the process of preference elicitation is more like preference construction.<sup>[15,42]</sup>

Finally, general population respondents could be provided with patient valuations. If so, these valuations should be obtained at different time points in order to reflect the differences between valuations during transition and those after a period of adaptation. The aim of achieving better informed preferences, however, is not to try to get the general population respondents to reproduce patient values; this would be better achieved using patient values directly. Rather, the purpose is to allow the general population to incorporate patient values into their own valuations. Menzel et al.<sup>[22]</sup> suggest (rather ambitiously) that the general population may be able to distinguish between appropriate and inappropriate adaptation. This would require information on the types of adaptation undertaken by patients, so that respondents could decide which adaptations they wish to take into account in their valuation. This is a substantial redesign of the current methods of eliciting preference, which, as Fryback<sup>[30]</sup> has pointed out, would require a major paradigm shift in this field.

## 7. Conclusions

NICE has patient representatives on the Appraisal Committees and Guideline groups in England and Wales, but in many ways it seems to be inappropriate that patient representatives should be involved in assisting in social decision-making using (the largely uninformed values) of the general population. A better model might be for patients to be more involved in the valuation of the health states and for a committee with representatives of the general population to judge the resulting assessment of cost effectiveness alongside other social criteria for resource allocation decisions. We believe that it would be better to integrate patient values into the assessments of clinical and cost effectiveness rather than have patient valuation as a separate exercise.

While the authors of this paper are not agreed on the extent to which patient values should be taken into account, or the most appropriate method, we have identified the need for greater debate and more research. This debate needs to be better informed since there is an important research agenda to pursue in understanding the causes of the differences between patient and general population values, which may have important normative implications. The research agenda needs to extend to ways of improving how we describe health states, the elicitation of patient values and developing methods for obtaining informed general population preferences.

There are some real concerns with the current use of largely uninformed general population values. However, on the other hand, there are reasons to be concerned also about the adoption of patient values based on lowered aspirations and their comparison group who may be in poor health. One solution discussed in this paper is to provide the general population sample with more information on the effect that the health state has on patients' lives.

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